

THE EFFECT OF PROSTATE CANCER SUPPORT GROUPS ON UNCERTAINTY
IN PROSTATE CANCER

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IN PROSTATE CANCER

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ABSTRACT

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Key words: **Prostate Cancer, Support Groups, Uncertainty**

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IN PROSTATE CANCER

by

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PREFACE

This study was conducted to determine the effectiveness of prostate cancer support groups in reducing the amount of uncertainty experienced by men with prostate cancer. It was designed to measure one area of potential benefit of prostate cancer support groups.

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To my wife, Vicki. Without her love and understanding this study would not have been possible.

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CHAPTER 1: Introduction

Background

In 1999 it was estimated 179,300 men would be diagnosed with prostate cancer (American Society[ACS] 1999). During the same period it was estimated 37,000 men died from this disease, the third leading cause of cancer death among men. In fact, the yearly mortality from prostate cancer trails only lung and colon cancers, with the incidence increasing exponentially with age. Incredibly, Pienta and Esper (1993) report that by age 80 approximately 60-70% of men, who died from other causes, had histologic evidence of prostate cancer at autopsy. Prostate cancer usually affects older men. Gregoire, Kalogeropoulos, and Corcos (1997) stated that 80% of prostate cancers are diagnosed in men over 65 years of age. They estimate the number of cases of diagnosed prostate cancer will increase threefold by the year 2030.

These statistics reveal a high incidence of a disease that, until recently, was given very little attention. Perhaps the advanced age at which most men are usually diagnosed or the relatively slow disease progression served to lessen the impact of this disease. The morbidity of the disease may also play an important role in the scant public discussion of prostate cancer as described by Kaps (1994). Complications of the disease and treatment include impotence and sexual dysfunction, varying degrees of incontinence, fatigue, and bowel problems. Many of these are too difficult and embarrassing for some men to discuss in public. Prostate cancer has subsequently received less attention than other cancers with a smaller prevalence in the general population, such as breast, liver, or pancreatic cancers. (ACS, 1999)

Support groups, designed to assist individuals in coping with illnesses, have been in existence for many years. Pratt, an internist in Boston, was credited with forming the first support group to assist tuberculosis patients in 1905 (Johnson and Lane 1993). With the aid of local clergy he held meetings to help patients deal with both the physical and psychological aspects of the disease. The validity of this support has withstood the test of time as support groups continue to focus on those same aspects of the specific disease. Katz and Bender (1976) have defined a support group as a voluntary, small group structure for the mutual aid and the accomplishment of a special purpose. Cancer support groups adhere to this by operating as a group in which the members become dependent on each other for psychological and social support. According to Cella and Yellen (1993) this is accomplished in four ways: offering direct assistance, giving advice based on their personal experience, providing emotional support, and providing a sense of belonging to the group. Individuals diagnosed with cancer seem to draw more benefit when others who share the same diagnosis provide these supportive measures. Cancer patients gain strength from each other when they realize they have a common bond. They empathize with each other and share ideas, fears, or concerns they may not feel comfortable discussing with anyone else. This draws members of the group closer together as they overcome obstacles and meet goals together.

Men have a difficult time utilizing cancer support groups. Cella and Yellen (1993) note that four times as many women use cancer support groups than do men. This ratio does not mean men do not need as much support as women, but rather reflects how uncomfortable men are in asking for help. As Kaps (1994) points out, older generations are especially unlikely to ask for help as they were raised to believe that men and boys do

not cry or talk about their feelings. This is perhaps one explanation for the historically poor attendance of men at support group meetings.

Groups providing support to prostate cancer patients face several problems. Men with prostate cancer hesitate to attend a support group meeting and once they do attend, they resist joining discussions involving their personal feelings. All cancers elicit anger, fear, confusion, and depression; however, prostate cancer carries with it additional concerns of impotence, incontinence, and bowel problems. These are concerns which men are very uncomfortable talking about and may further limit their group participation.

Prostate cancer support groups such as *Us Too* and *Man to Man* have confronted these problems directly, using an educational format to overcome barriers present among men in general. Their meetings focus on a presentation by a health care professional regarding aspects of prostate cancer. They usually conclude with social time for the attendees to informally talk with other members or health care professionals at that meeting. As a result relationships among members are developed, social supports are established, information is exchanged, and a sense of belonging to the group is established.

According to Cella and Yellen (1993), cancer support groups work to improve social support, decrease isolation, serve as a buffer against stress, provide assistance, and reconcile emotional conflicts of members. Prostate cancer support groups add an additional quality perhaps not found in other support groups. Through the education provided at each meeting, the members become more aware of the management of their disease, and often begin to take a more active part in the management of their disease. Kaps (1994) writes, By becoming informed survivors, we have become informed

patients. It is good to be able to sit down and have a dialogue with our physicians. Together, we now decide on the best course of treatment for our particular case. Having an active role in this decision-making process and a clear understanding of the ramifications of the treatment and its after effects is so important. It erases misunderstanding and fear . Assuming this is true it stands to reason that patients involved in this type of support group experience less uncertainty toward their disease. Patients not actively involved in a support group would have more uncertainty and understand less what it means to have prostate cancer.

Purpose

The purpose of this study was to compare the amount of uncertainty experienced by men with prostate cancer attending a support group and those with prostate cancer who do not.

Research Question

The research question was a null hypothesis: No difference exists between the uncertainty of prostate cancer patients involved in a cancer support group and those who are not. In this study the dependent variable is the score each respondent receives on the Mishel Uncertainty in Illness Scale Community form (MUIS-C) and the independent variable is active participation in a prostate cancer support group. The study measured what effect group participation had on the uncertainty experienced by individuals with prostate cancer. Thus the research question was: What effect does participation in a support group have on the uncertainty patients experience with their disease?

Volunteers were solicited from the Walter Reed Army Medical Center - Us Too, Inc. prostate cancer support group. Men were asked to volunteer during a regularly scheduled meeting. However, since attendance at the meeting was low, a survey was also mailed to 30 randomly selected members on the group mailing list. Individuals not participating in a support group were captured through a random survey of men registered with the Center for Prostate Disease Research (CPDR), also a subsidiary of Walter Reed.

Several extraneous variables existed which had to be controlled to increase the validity of the study. For example, the period of time since the patient was diagnosed is an important variable. A newly diagnosed patient, who had not yet completed treatment, may have biased the data as they are in the initial stages of learning about their disease. Uncertainty at this time is expected. To control for this, any patients less than six months from the date of prostate cancer diagnosis was excluded from the study. Similarly, those attending their first support group meeting were also excluded, as they would not have had time to receive the full benefit of group participation. To help identify variables that may confound the study results, demographic information was collected on each respondent. This information included age, marital status, other family members with the disease, severity of disease via Gleason score, ethnicity, religious preference, etc. This information was then analyzed, looking for trends in the data that may reveal more information on factors affecting uncertainty in prostate cancer.

Theoretical Framework

This study utilized the Mishel Uncertainty in Illness Model, which has been used extensively to study uncertainty in a variety of malignant neoplasms to include breast, colon, and gynecologic cancer. The model describes the cognitive state created when individuals cannot adequately structure or categorize an event due to lack of sufficient cues. Uncertainty occurs in situations where the decision-maker is unable to assign definite value to objects or events and/or is unable to accurately predict outcomes.

Mishel (1988) defined uncertainty as the inability to determine the meaning of illness-related events. The uncertainty theory was developed to explain how patients cognitively process illness-related stimuli and construct meaning for the illness event. Uncertainty is composed of three major components: stimuli frame, structure providers, and cognitive capacities.

According to Mishel (1988), stimuli frame consists of symptom pattern, event familiarity, and event congruence. These components are inversely related to uncertainty and provide additional information about the illness. The symptom pattern information relates to physical sensations experienced. Event familiarity is concerned with the actual health care environment. Finally, the predictability and stability of the stimuli affect event congruence. In relation to prostate cancer the symptom pattern is variable depending upon the severity of the disease and the treatment chosen, resulting in increased uncertainty about the disease. Event familiarity is developed over time through experiences within the structure of the health care environment, complexity of cues, and novelty of events. Interpretation of the uncertainty is affected by information related to a previous illness experience,

familiarity with a health care practitioner, and cultural as well as social factors.

Complexity of cues resulting from inconsistent results from multiple tests in a prostate cancer work-up can increase uncertainty. Event congruence refers to the consistency between the expected and the experienced in illness-related events.

Structure providers, the second component of uncertainty that includes three sub-levels: credible authority, social support, and education positively affect the stimuli frame. Health professionals, family and friends familiar with prostate cancer, and educators serve as information sources that can directly and indirectly affect knowledge about the stimuli frame components. Credible authority is an essential component of uncertainty for men with prostate cancer. Patients rely on health care providers for clarification of laboratory test results and interpretation of the meaning of symptoms associated with their health. Mishel (1988) also notes social support can directly and indirectly influence ambiguity, complexity, and unpredictability factors related to uncertainty in illness. Previous experience with a friend or relative who has had prostate cancer often provides the frame of reference for many men as they learn and come to understand their disease. Unfortunately, some information obtained through this support network may not be accurate and may lead to false assumptions, which may have a negative impact on their health care.

Cognitive capacities, the third component of uncertainty, may positively affect evaluation of the symptom pattern, event familiarity, and event congruence. Nursing assessments to determine comprehension and retention levels of prostate cancer information during follow-up care can assist the patients with accurate knowledge and emotional support.

Definitions

For the purposes of this study, support group was defined as any collection of individuals that met on a regular basis, regardless of size. The purpose of the meeting was : to provide a forum for individuals to express feelings and concerns about living with cancer and its risks, facilitate mutual support among group members facing similar problems, provide accurate information about the ramifications of cancer and treatment options, and finally, help members increase their coping skills.

Within the framework, uncertainty was defined as the individual s inability to determine the meaning of illness-related events.

The term survivor was used to describe any living person who had been diagnosed at one time with prostate cancer. It does not make any reference to their current health status, or the process of their disease progression.

Assumptions and Limitations

The first assumption of this study was that a diagnosis of prostate cancer would result in feelings of uncertainty for that individual. This may be uncertainty regarding how the disease will progress, how it will effect them physically, how its treatment will effect them physically and emotionally, and how much longer they will live.

Second the study assumes that joining and actively participating in a support group reduces the amount of anxiety experienced by the individual. This would result in the treatment group having a lower uncertainty score on the MUIS-C.

Finally, the foremost assumption of this study was that differences detected in the individuals in the experimental and control groups did not exist prior to joining the support group. It is conceivable only individuals with higher levels of uncertainty are

compelled to join and participate in a support group. Therefore, participants in the support group may reflect higher uncertainty scores; however, they may actually be low when compared to the uncertainty they had prior to joining the group. It is also possible that only those men with more education, a factor that lowers uncertainty, will seek out a support group and the information it can provide.

The study had several limitations. First, baseline data was not obtained on the experimental group prior to participation in a support group; therefore, the study did not measure changes in uncertainty before and after group participation. It was a retrospective purposive study, using the case control design. It was not be feasible to select subjects for each group in a random manner. Time and budget limitations mandated a purposive sample. The study also looked only at prostate cancer patients in the military health care system from the Washington D.C. area. This may limits the ability to generalize the findings to the genral population.

CHAPTER II: REVIEW OF THE LITERATURE

Introduction

Cancer elicits many responses in those whom it has afflicted. Fear, anxiety, helplessness, depression, and uncertainty have been documented in many patients. The medical and nursing communities have worked tirelessly to assist patients as they try to understand and cope with their disease. This study evaluated one intervention, a support group, and its ability to reduce the amount of uncertainty experienced by men with prostate cancer.

The review of the literature examined what constitutes a support group and what benefits can be derived from such groups. Articles examining uncertainty in various types of cancer were also reviewed. It should be noted, however, data regarding prostate cancer support groups and uncertainty in prostate cancer are limited at this time.

Support Groups

Much has been written regarding the components of effective cancer support groups. A landmark article written by Cella and Yellen (1993) highlights the unique stress cancer puts on the individual. The authors note that the stress of cancer compares to the stress a war veteran feels after returning from battle; only those who have experienced cancer and its treatment can truly appreciate the stress. Helping individuals cope with this stress is a goal of cancer support groups. These groups allow cancer patients to share their experiences in a group setting. However, the authors point out several components are necessary for a support group to be successful. The first is the need for the group to function on the basis of mutual aid. The concept of mutual aid used by the authors refers to any gathering of people who depend on each other to accomplish a common goal.

According to the authors, mutual aid can be provided by direct assistance, advice based on personal experience, emotional support, and a sense of belonging to the group.

Cella and Yellen (1993) also identify barriers to joining support groups. First, physicians using the medical model focus on the individual and not on groups or group support. Second, the mental health community has traditionally focused group therapy to stimulate changes in the individual, rather than provide mutual support. A third barrier relates to health care costs; the cost of obtaining professional counseling is often not covered by insurance. The individual fears of obtaining professional help will only add to their financial burden. Finally the authors state many cancer patients mistakenly believe the efficacy of support groups is not yet proven. However, there are many well-controlled studies with randomized assignment of study subjects, which have shown improvement in the quality of life of support group participants.

Finally, Cella and Yellen (1993) emphasize the important role of the group facilitator. They state the facilitator should ensure all participants are given a chance to speak, promotes an accepting environment for individual feelings, and answers members questions when they arise.

Johnson and Lane (1993) also documented the important role of support groups in cancer care by providing information, support, advocacy, socialization, and affirmation of feelings. The authors identified many different types of support groups. For example, some are open to patients with any stage or type of cancer, family members, or friends of cancer patients; the common denominator for participation in these groups is personal experience with cancer. Some groups offer education to members, while others are geared more toward individualized support.

Johnson and Lane (1993) identify four objectives that provide the foundation of any group. First, the group must provide encouragement for people to express their feelings, facilitate mutual support among group members facing similar problems, provide accurate information about cancer and treatment options, and help members strengthen their problem solving and coping skills. Next, the authors discuss important qualities facilitators must possess. They must be enthusiastic. Some enthusiasm nurtures the group and is therapeutic. Facilitators must have group-leadership skills. This allows them to ask leading questions, actively listen, restate, clarify, summarize feelings, and give feedback. Finally, facilitators are responsible for creating an atmosphere in which the group can collectively thrive. The authors conclude by stating the therapeutic power of the support group arises from assuring its members they are sharing in a special journey together.

Several studies have been conducted to examine the benefits of support group participation in cancer patients. Gregoire and colleagues (1997) reported the effectiveness of a professionally led support group for men with prostate cancer. In their three-year study 54 men participated in seven separate support groups. These support groups met once a week for 10 weeks and were led by a urology nurse and a psychologist. The groups were small ranging from eight to 10 men each. Medical information on prostate cancer and its treatment was largely provided by medical guest speakers. A questionnaire was used to evaluate the effectiveness of the support groups. The results revealed 66% rated the support group as extremely informative and educational, 94% stated the group improved their knowledge of prostate cancer, 91% reported it improved their understanding of prostate cancer treatments, 80% stated the

information given by the group enabled them to be more actively involved in their treatment, and 86% reported the group enabled them to better cope with their illness. This study clearly highlights some of the expected gains from participation in a cancer support group.

Evans and Connis (1995) studied the effects of group therapies for depressed cancer patients receiving radiation treatment. In their study 78 depressed cancer patients scheduled to receive radiation therapy were randomly assigned to two treatment groups and one control group: 29 to a cognitive behavioral treatment group, 23 to a social support group, and 26 to a control group. At the time of entry and at eight weeks and six months each participant completed four measures administered in a single session. During the study two participants died and four became too ill to complete the follow-up measures. The results showed depressed persons with cancer who received brief group therapy demonstrated greater reduction in emotional stress than the control group members who did not receive any therapy. Although both treatment groups showed reduced distress, the social support group therapy produced favorable change on more dimensions of adjustment for more participants than did the cognitive behavioral group.

Gray, Fitch, Davis, and Phillips (1997) reported a qualitative study they conducted of breast cancer self-help groups that were not professionally led. Twenty-four women were surveyed regarding their experiences with breast cancer self-help groups. The results were reported in three broad categories: emotional support benefits, informational and practical benefits, and group processes and structures. In the category of emotional support benefits, women reported they benefited from being with other women who were also struggling with breast cancer. They also voiced their appreciation of the similarities

shared with other women in their self-help group. Other women talked about the importance of laughter during group sessions and how it seemed to balance the deep sorrow they had about their diagnosis. Many women also described the hope they felt at each meeting when they saw long term survivors of breast cancer. It encouraged them to believe they also could survive.

Under the category of informational and practical benefits, women described how they learned a lot about their disease by attending support group meetings. They reported they learning about aspects of their disease and treatment that could only be related by someone who had live through it. Many appreciated the information they were able to gain from the meetings about unconventional therapies and how to gain access to community resources.

Within the category of group processes and structure the women reported the group gave them a separate place to deal with issues, so that they did not feel the need to burden their family and friends. This become more evident as more time passed after their original diagnosis, when family and friends wanted everything to return to normal, which created a disparity between the needs of the family or friends and the needs of the breast cancer survivor. Death of another group member provoked a variety of feelings. Many felt the death of a member dragged down the whole group and made them feel more depressed, while others believe the death of a member underscored how limited they felt in discussing their feelings with the rest of the group. The authors concluded support groups helped women overcome the stigma of breast cancer by making them feel less alienated and isolated by their disease and more assertive toward health care professionals managing their care.

Uncertainty

Wong and Bramwell (1992) utilized Mishel's theory on uncertainty in illness when measuring uncertainty in breast cancer survivors after a mastectomy. Using an instrument developed by Mishel the study measured the uncertainty of 25 women admitted to two acute-care teaching hospitals for their first partial or modified radical mastectomy. The researchers hypothesized a difference existed in the uncertainty experienced by women one to two days before and one to two weeks after discharge from the hospital. The results of the study did not show a significant difference in the perceived uncertainty experienced by the subjects. The authors acknowledge this may reflect uncertainty is a continuing problem for this population.

Deane and Degner (1998) examined uncertainty in women who had a breast biopsy with a benign outcome. The study sampled 70 women who in part were required to complete the MUIS- Community Form (MUIS-C). This tool is tailored for use in the outpatient setting. The purpose of the study was to describe the information needs of women who had a breast biopsy with benign outcome and to evaluate the related uncertainty and anxiety they experienced. The researchers determined the most important learning need of the women in the sample was knowing when they would learn the diagnosis.

Summary

In summary, the literature clearly reveals the benefits of participation in a support group. The concepts of mutual aid, providing a forum for expression of feelings and reduction of emotional stress have all been well documented. Studies have also shown uncertainty can be effectively measured in both the inpatient and outpatient population;

however, the literature has not completely addressed how to manage high levels of uncertainty when it is found. This study measured the effect of one intervention, support group participation, on the uncertainty experienced in an outpatient setting by survivors of prostate cancer.

CHAPTER III: METHODS

Introduction

This study focused on differences in uncertainty experienced by men with prostate cancer participating in a support group and those who do not. Mishel (1981) has theorized uncertainty produces a stress response in individuals when they are unable to adequately structure or categorize events because sufficient cues are lacking. Men with prostate cancer frequently face uncertainty in the form of ambiguity, vagueness, unpredictability, and lack of important information about this disease.

Research Design

Using a case control design, two groups of men with prostate cancer were selected as study subjects. One group consisted of those who participate in a prostate cancer support group and the second group of those who have elected not to join in a support group. Those not participating in a support group served as the control group for the study. The men participating in a prostate cancer support group composed the participation group. Thus, the independent variable for this study was regular participation in a prostate cancer support group. The uncertainty experienced by each group was measured and the resulting data on differences in uncertainty were statistically analyzed, measuring the relationship between participation in the support group and non-participation. This chapter describes the sample, setting, measurement methods used, data analysis, and a time line for this study.

Sampling and Setting

A voluntary convenience sample of men with prostate cancer was obtained from the urology clinic of a large military medical center in the Northeastern United States. The clinic treats a large number of men with prostate cancer and sponsors a large prostate cancer support group. The clinic is also closely associated with the Center for Prostate Disease Research (CPDR). Using a database at the CPDR a survey was mailed to 100 men who had been diagnosed with prostate cancer at least six months earlier. Men indicating they have never attended a support group composed the control group. The participation group was composed of men who indicated in their survey they actively participate in a support group and have attended more than one meeting. The prostate cancer support group associated with the urology clinic was also surveyed during a regularly scheduled quarterly meeting to increase the number of men in the participation group. However, due to poor attendance at the meeting a survey was also mailed to 30 randomly selected individuals from their mailing list. Included in the participation group were those men who had been diagnosed at least six months prior to completing the survey and have attended at least one previous meeting.

A total of 85 completed surveys were received. Twenty indicated they were active members of a support group and were included in the participation group. Sixty-five indicated they did not participate in a support group and were included in the control group.

Measurement Methods

The study utilized the Mishel Uncertainty in Illness Scale Community Form (MUIS-C) published in 1986. The scale was designed to specifically measure uncertainty in an outpatient setting. Frequently in an era of managed care, those with chronic disease are required to manage their diseases as an outpatient. Consequently, an instrument was developed to assess the uncertainty experienced by this population. The resulting instrument is a 20 item questionnaire, using a 5 point Likert type scale. The MUIS-C has been used in numerous studies, the standardized alpha ranges from a low of .53 in one study to a high of .92 in several other studies. In 20 studies the average alpha was .83. In this study the scale was expanded to capture demographic data, such as marital status, considered influential to the uncertainty experienced by each respondent.

Protection of Human Rights

The study was scrutinized by the Internal Review Board (IRB) at both the Uniformed Services University and Walter Reed Army Medical Center. The purpose and objectives of the study were explained to all potential subjects in a cover sheet included with each survey. If the individual completed and mailed the questionnaire, it was construed as consent and permission to use the data provided. The tool did not ask for names, social security numbers or other data that could lead to identification of the respondent. The tool also did not ask any sensitive questions for which the respondent might risk embarrassment or criminal prosecution. No records were kept of who had been sent a survey to further ensure confidentiality.

Plan for Data Analysis

All data was coded and entered into Statistical Program for the Social Sciences (SPSS 9.0). Differences in uncertainty scores between the two groups were tested for statistical significance using appropriate statistical tests. Variables such as age of the respondents, marital status, support system in place, and severity of disease were analyzed by analysis of variance to determine interactions with the main independent variable, participation in support groups. All relevant data were summarized and presented in frequency distributions and in graphs.

CHAPTER IV: ANALYSIS OF DATA

Introduction

The purpose of this study was to measure differences in uncertainty experienced by men with prostate cancer participating in a support group and those who do not. The study utilized the Mishel Uncertainty in Illness Scale — Community form (MUIS-C), a tool extensively used in the literature to measure uncertainty in chronic diseases. Uncertainty is an important obstacle to overcome when coping with a long-term illness. This chapter provides a description of the sample, population, demographics, and scores on the MUIS-C.

Sample

The study surveyed men with prostate cancer who had been diagnosed at least 6 months prior to the date they filled out the survey form. The sample was divided into two groups: those who were members of a support group and those who were not. To be included as a member of a support group, the individual must have attended at least one previous support group meeting. Also, he must have had the diagnosis of cancer for at least 6 months. For inclusion in the control group, the individual had to have been diagnosed with prostate cancer at least six months earlier and had not participated in a support group. These qualifications allowed for the control of initial uncertainty of diagnosis with a new disease, as well as the effect of a support group, if any, to begin. The study used the MUIS-C, which was a tool designed to measure the level of uncertainty in those with a chronic disease in an outpatient setting. The scores of each group were then compared to determine if those in a support group had lower uncertainty.

A total of 89 men completed the MUIS-C. Of the 89, 20 were members of a support group while 69 were not. Of those in a support group, seven were surveyed during a regularly scheduled, quarterly meeting. To augment the sample of those in the support group, forms were also sent to 30 randomly selected members of the group. Twenty-two of the mailed forms were returned. A surprising result was 15 of these denied they were members of a support group. An investigation into this found that names of individuals, who might benefit from a newsletter published by- the support group, are often added to their mailing list. These men may not have had prostate cancer and, if they did, may or may not have joined the support group. The newsletters contain short articles written by an urologist discussing treatment options and summarizing new research findings in prostate cancer. The final sample included 14 men who had participated in the support group and 15 who had not.

In order to increase sample size, a second mailing of survey forms was done. One hundred names of men diagnosed with prostate cancer, who had previously agreed to participate in prostate cancer research, were randomly selected from a list provided by the Center for Prostate Disease Research (CPDR), a component of Walter Reed Army Medical Center, formed specifically to conduct prostate cancer research. The CPDR maintains a database of men diagnosed with prostate cancer who have formally consented to participate in prostate cancer research. To prevent any overlap of respondents from the previous survey sample, the questionnaire asked the individual not to respond if they had previously completed this survey. This mailing netted a response of 60 forms, a 68% response rate. Of this number, six reported they were members of a support group, while

54 were not. Thus the final sample became 20 in the treatment group and 69 in the control group.

Demographics

The inclusion of demographic variables in the survey forms provide a description of the respondents. Their ages ranged from 51 to 86 years. The average age was 70. The advanced age of the respondents was expected since prostate cancer, is largely a disease of older men. Eighty respondents indicated they were married, while nine were single. Similarly, eight individuals reported they lived alone, while 81 reported they did not.

Eight respondents reported a high school education only, 15 had some college education, while 65 surprisingly reported having graduate education. Finding such a high level of education among respondents was unusual.

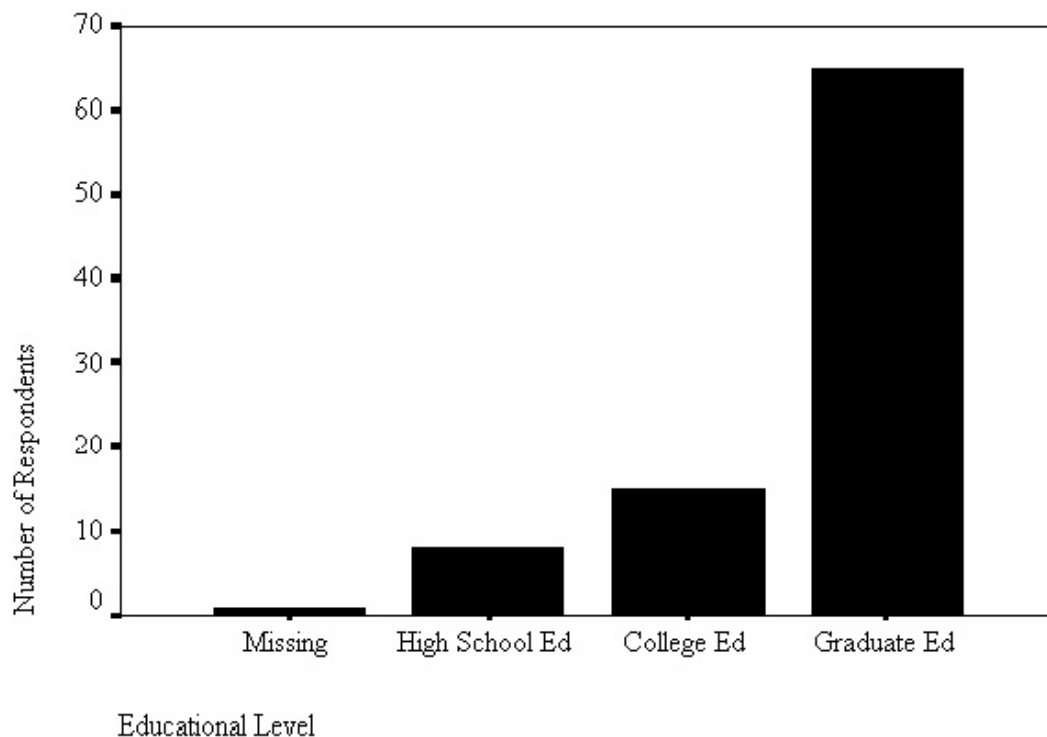


Figure 1.

Educational Level of the Respondents

In terms of ethnicity, 12 reported they were African American, one was Asian, one Hispanic, and 75 were Caucasian.

For religious preference, 52 reported they were Protestant, 28 were Catholic, three were Jewish, five had no preference, and one individual stated he belonged to a group other than those previously mentioned.

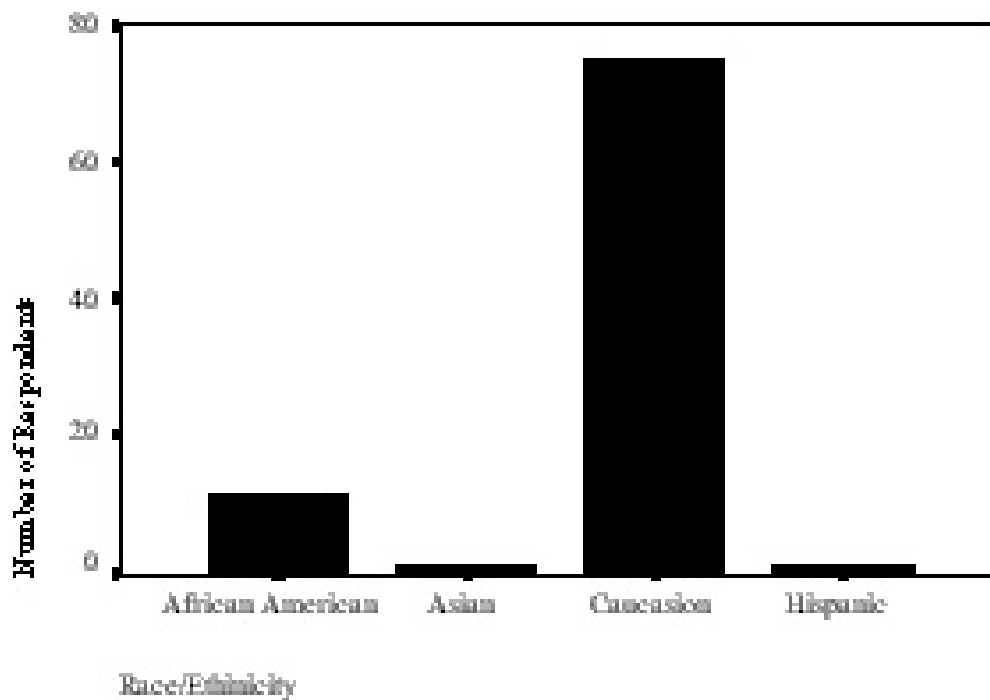
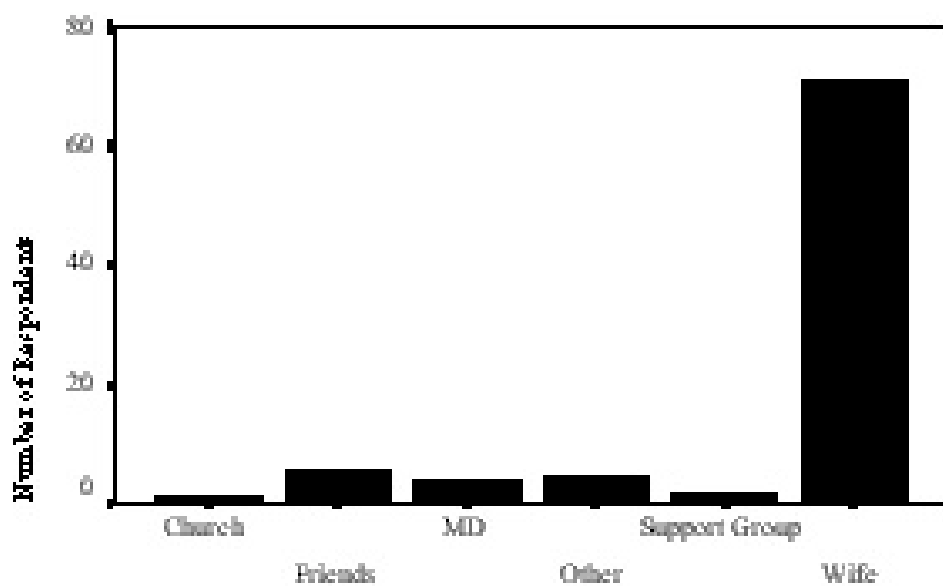


Figure 2.

Ethnicity of Respondents

Regarding who provides the most support for them 71 reported it was their wife, six reported it was their friends, four stated it was their physician, two said it was their support group, one said it was their church, and five thought it was someone other than those previously mentioned.



Who provides the most support to you

Figure 3.

Providers of Support to Respondents

The amount of time spent in a support group varied from three months to 10 years. Only one individual had been in the support group less than one year, while 11 reported they had been members for two to four years, four had been members for five to seven years, and five reported they had been members for eight to 10 years.

The respondents were also asked if they had any family history of prostate cancer. Sixty-seven reported no family history, and 19 reported there was. Three individuals left this question blank.

Because the sources for all names used for the mailings were military, the survey asked if their status was active duty or retired. All responses indicated they were retired. Additionally, they were asked which branch of service they had belonged to. Fifty-eight reported they were in the Army, 17 reported Air Force, 12 Navy, and two were in the

Coast Guard. The individuals were also asked to indicate their rank while they were in the military. Nineteen reported they were enlisted, 67 were officers, and three were warrant officers.

Finally, the survey asked what stage their disease was at the time they were diagnosed and how long ago that happened. None of the respondents could accurately state what stage of disease they had using the Tumor Node Metastasis (TNM) system, or the Gleason score; therefore, that question was deleted. Thirty-five indicated they had been diagnosed less than five years earlier, 33 had been diagnosed five to nine years earlier, and 19 reported they had been diagnosed more than 10 years earlier. Two individuals did not answer the question.

Analysis of Uncertainty

The purpose of the study was to measure differences in the levels of uncertainty in prostate cancer patients who are members of a support group compared to those who are not. The results showed no statistically significant differences between members of the two groups. In fact the scores of the two groups are nearly mirror images of each other. Applying a *t*-test to the difference of the group means, indicated no statistically significant relationship between uncertainty and membership in a support group. Data from the two groups resulted in a P value of 0.195, indicating no relationship between uncertainty and membership in a support group or amount of time spent in a support group.

In general the uncertainty scores for most respondents were low. Using the MUIS-C, the lowest possible uncertainty score is 23 and the highest is 115. The higher the uncertainty experienced by the respondent, the higher the score. Sample had an average

uncertainty score of 45 with a range of 23 to 77. Among those in a support group, the average uncertainty score was 48.2. The control group had an average uncertainty score of 44.7. Therefore, the differences between these two groups were very small.

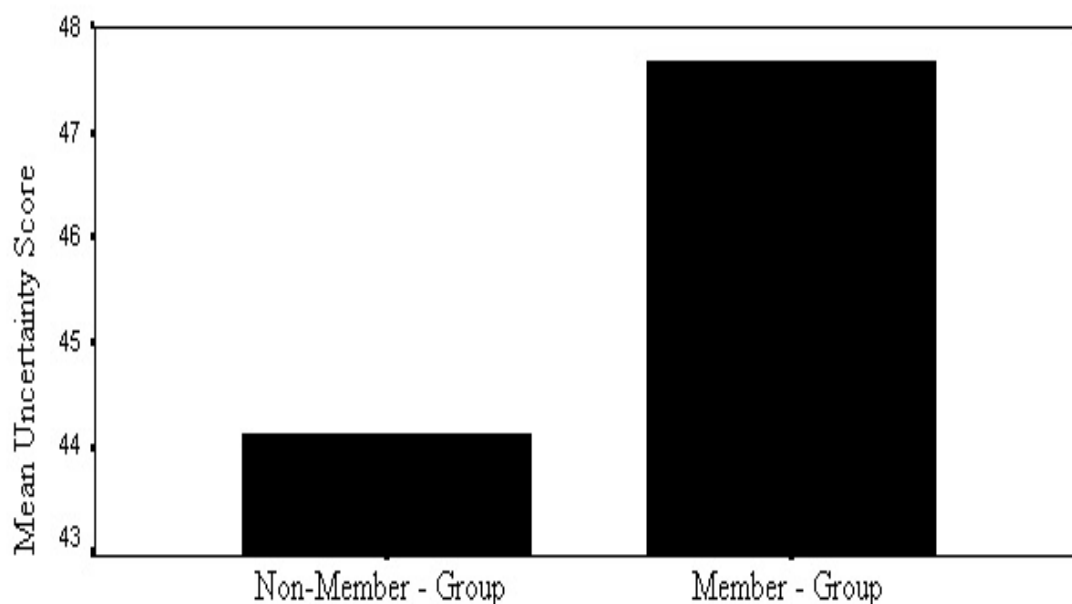


Figure 4

Uncertainty Scores for Members and Non-Members

The amount of time spent in a support group also seemed to have little impact on the uncertainty experienced by the individuals. Those members of a support group who had been active members less than five years had an average uncertainty score of 46.1. Members of the support group active for more than five years had an average score of 50.4. The difference between these two groups was not significant.

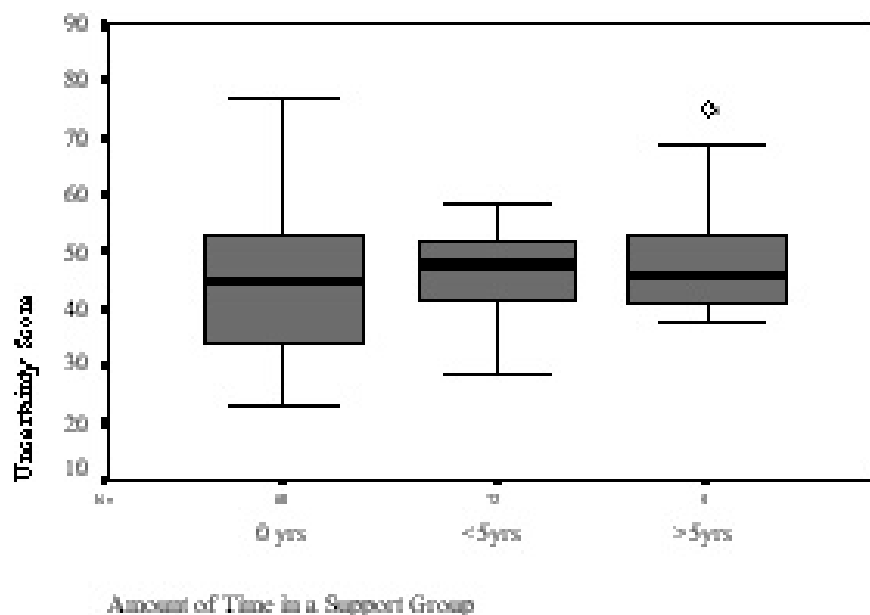


Figure 5.

Uncertainty Scores and Time in a Support Group

Similarly, marital status was not an accurate predictor of uncertainty levels. Married individuals had an average uncertainty score of 45.4, while those who were single had an average score of 45.8. Once again, these scores are not statistically significant. Interestingly, of those who reported that they were married, 100% stated they received most of their support from their wives.

Although, Mishel (1988) has reported that the educational level of the individual and their measured levels of uncertainty are inversely proportional, it was not the case in this study. All educational levels reflected low uncertainty scores. Those with a high school education had an average uncertainty score of 47.4, those with a college education had 48.6, and those with a graduate education had an average score of 44.6.

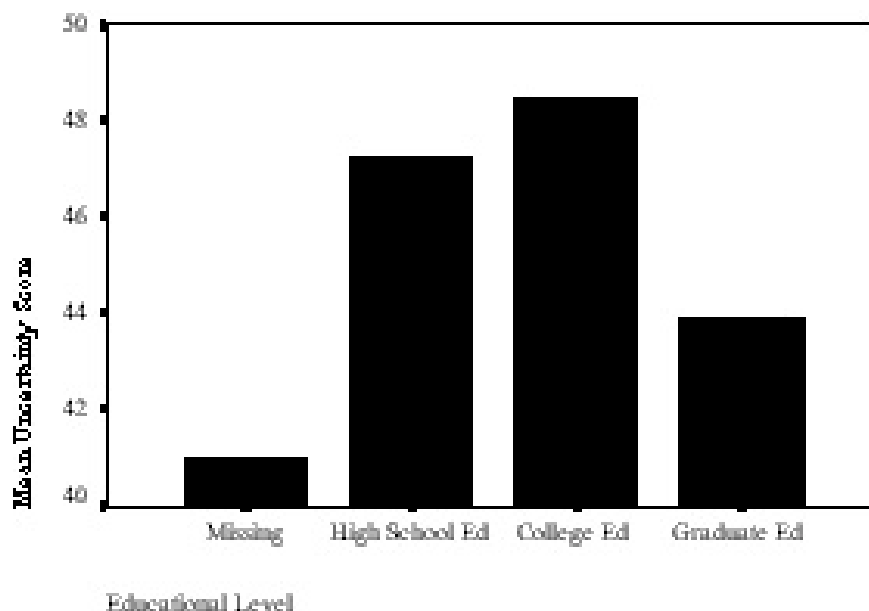


Figure 6.

Mean Uncertainty Score for Education

A family history of prostate cancer also did not seem to impact the level of uncertainty the individual experienced. Those who had a history of prostate cancer in their family had an average uncertainty score of 50.0; those who had no such history had an average score of 45.3.

Finally, the amount of time that had passed since the individual had been diagnosed also seemed to have little relevance to the overall uncertainty of the individual. Those who had been newly diagnosed seemed to have just as low an uncertainty score as those who had had their disease for many years. Those who had been diagnosed less than five years earlier had an average uncertainty score of 43.9, those diagnosed five to nine years earlier had an average score of 44.6; those diagnosed more than 10 years earlier had an average score of 50.3.

Summary

In summary, 89 questionnaires were analyzed to determine levels of uncertainty for the respondents. The level of uncertainty in this sample was very low. The study did not show a statistically significant difference in the uncertainty scores of those who were members of a support group and those who were not. The study also did not show significant differences in the uncertainty scores of the sample members when analyzed according to a variety of demographic data. The study suggested that uncertainty was not an issue among individuals who were diagnosed with prostate cancer.

CHAPTER V: CONCLUSIONS AND RECOMMENDATIONS

Introduction

The purpose of this study was to measure differences in uncertainty experienced by men with prostate cancer participating in a support group compared to those who do not. The study utilized the Mishel Uncertainty in Illness Scale — Community form (MUIS-C), a tool extensively used in the literature to measure uncertainty in chronic diseases. Whereas uncertainty is an important obstacle to overcome when coping with a long-term illness and other forms of cancer, no current data were found regarding uncertainty among those with prostate cancer.

The methodology for this study consisted of distributing questionnaires (see Appendix A) to members of a prostate cancer support group during a regularly scheduled quarterly meeting. The form was also mailed to 30 randomly selected men from the support group mailing list. To increase the size of the sample, a second mailing was made to 100 randomly selected men from a list of individuals with prostate cancer provided by the Center for Prostate Disease Research (CPDR). The questionnaires were then scored. A mean uncertainty score for each individual answering the survey was computed from the responses to the MUIS-C.

Uncertainty Scores

The study results support the null hypothesis that no statistically significant differences exist in the uncertainty levels of those affected by this type of cancer whether in a support group or not. The uncertainty scores, for the entire sample, were low. The lowest possible score for this survey was 23 and the highest was 115. However, with this sample the average score was 45, with a range of 23 to 77. This leads to speculation that perhaps uncertainty is not a problem for prostate cancer patients.

A surprising finding was the unusually high educational level of those responding to the survey. Sixty-five of 89 respondents, or 73%, reported that they had a graduate level education. Perhaps there was an error in reporting educational attainment through misunderstanding the educational levels. However, a more likely explanation is that all respondents, in this study, had retired from the military. Education is an important factor for promotion during a military career thus sample members would be likely to pursue advanced education. The fact that higher levels of education result in lower uncertainty scores was confirmed by Mishel (1984)

An important finding among those respondents who were married was they depended on their wives for most of their support. This was also found among those who were members of a support group as they also reported that their wives and not the support group provided the most support for them. These numbers may be influenced by the frequent practice of having the husband and wife attend the prostate cancer support group meetings together. This would allow the couple to enjoy the benefits of the group, while maintaining the spouse's role of providing emotional support. Overall, a total of 71 of the 89, or 80%, reported their wives gave them the most support.

Race and cultural differences did not seem to play a big part in the uncertainty of the prostate cancer patients. The scores were equally low as can be seen in the following graph.

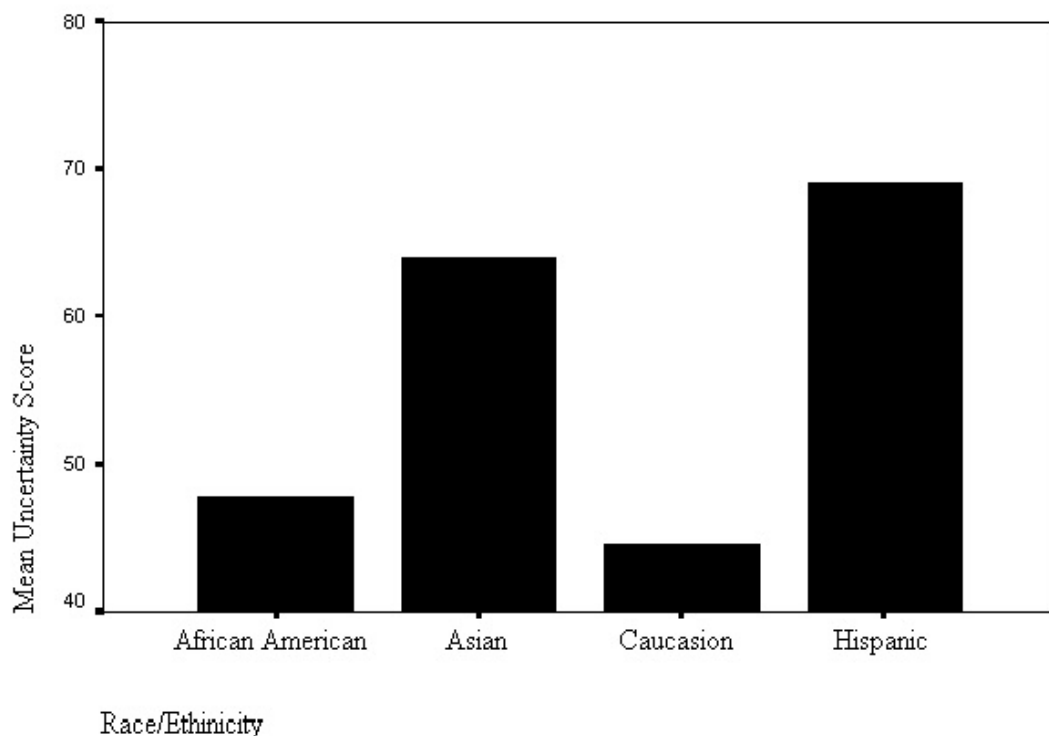


Figure 7

Uncertainty Scores and Ethnicity

An interesting and unexpected finding of the study was that many men who have had a prostatectomy not only considered themselves cancer free, but free from worrying about the disease in the future. Whereas some were always concerned, when their Prostate Specific Antigen (PSA) levels are drawn, that their cancer may return, others, it appears, are not concerned at all. They do not feel they ever need worry about prostate cancer again. While many men may remain cancer free, follow up lab work, specifically a yearly PSA level, is considered a cornerstone of disease management. Any PSA reading greater than zero after a prostatectomy indicates metastatic prostate cancer. The question then is whether these men are following their PSA levels after surgery as their urologist

has directed them. Although not directly questioned in the survey, several men commented they did not feel this survey was applicable to them because they had their prostate removed and no longer needed to worry about prostate cancer. One individual wrote, This survey does not apply to me. My prostate was removed at Walter Reed in May 1995 . A second respondent wrote, I read the attached questionnaire and feel it does not pertain to me. My wife and I talked over the best option we were sure would get rid of the future possibility of cancer. I had surgery (prostatectomy) three months later. However, Mishel (1997) reports a positive association between uncertainty and severity of illness. She cites other studies that have found recurrence of a disease or repeat hospitalization for the same illness correlate with higher uncertainty scores. Perhaps prostate cancer patients have lower levels of uncertainty due to the long, slow course of the disease or perhaps this sample had a very low recurrence rate.

Recommendations for Practice

An important finding was that the wife provides most of the support for prostate cancer patients, even when the individual is a member of a support group. This highlights the importance of ensuring the spouse is present at the time of diagnosis and during follow-up visits. As the main source of support for these patients, their need to be included in all aspects of their husbands care cannot be over emphasized. Allowing the patients to have their support system in place, from the first moment they are made aware of the disease, can be important to the patient as they come to terms with the disease.

Secondly, the findings substantiate the importance of providing resources to the patient and his family. The sample members in this study were highly educated with 73% reporting a graduate level education. The combination of patient handouts, selected articles, and Internet web site addresses can provide the patient and their family the

resources they need to decrease anxiety, uncertainty, and fear. Allowing them to educate themselves about prostate cancer, its diagnosis, and treatment will allow the patient and family to lower their level of uncertainty.

Recommendations for Future Research

In future studies, the population should be surveyed in the first months after diagnosis. During this time, uncertainty would be expected to be high. Surveying the population at this time might allow the reduction of uncertainty to be recognizable. To control for more extraneous variables, a population of newly diagnosed patients could be given the MUIS-C as they first cope with the disease. A selected portion of the population could then be assigned to the support group intervention and their uncertainty reevaluated. Comparing the uncertainty levels among members of this group to a randomly allocated control group would allow a better comparison of how support groups affect uncertainty in the prostate cancer population at a time when uncertainty would be expected to be bigger issue.

A future study that gathers data from a source which is not exclusively military might produce a sample more reflective of the general population. This population not only possessed a high level of education, but also a military retirement income, which may put them in a higher socioeconomic status. The sample used in this survey possessed demographic features which may result in low uncertainty scores without any interventions. Gathering data from nonmilitary populations may control these possible biases.

It may also be that uncertainty is not significant problem for men with prostate cancer. Perhaps future research should be directed toward qualitative studies that can highlight

the intangible benefits of a support group. Benefits such as emotional catharsis, camaraderie, and feelings of community are of tremendous benefit to those with cancer, although not easily measured in a quantitative study.

Summary

This study found that belonging to a support group did not have an impact on the amount of uncertainty felt by men with prostate cancer. However, those respondents not in a support group also had very low scores on the MUIS-C. The reality that, in general, the total sample had very low uncertainty scores indicates that perhaps this was not the most sensitive variable to measure the beneficial impact of support groups.

Cancer supports groups are unquestionably beneficial to the members who actively participate. If they did not provide some benefit to the members, they would quickly cease to exist. Although this study did not find a measurable difference in uncertainty scores, healthcare providers should continue to encourage their patients to participate. The concept of mutual aid described by Cella and Yellen(1993) can have multiple benefits for the individual when coping with chronic disease. Certainly, nothing is more reassuring than talking with others who may share a common experience.

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APPENDICES

Appendix A: Study Information Sheet

Appendix B: Demographic Data

Appendix C: Mishel Uncertainty in Illness Scale - Community Form

Appendix D: Data Dictionary

Appendix E: USUHS IRB Approval

Appendix F: Walter Reed Army Medical Center IRB Approval

Appendix G: MUIS-C Permission

APPENDIX A

Study Information Sheet

You are being asked to participate in a research study. Before you decide to be a part of the study, you need to understand the risks and benefits so that you can make an informed decision. This is known as informed consent.

The Department of Nursing of the Uniformed Services University of the Health Sciences is carrying out this study to examine the uncertainty felt by prostate cancer patients. Furthermore, we wish to identify factors that have an impact on the uncertainty each patient feels. The results obtained from this study will not only guide future research, but will also impact how health care professionals interact with prostate cancer patients in the future to minimize their uncertainty.

Participation requires completion of a survey that asks personal information, such as your age, marital status, do you live alone, and religious preference, and a second section which asks questions to allow us to measure uncertainty experienced by each respondent. You may withdraw from the study at any time. All data collected will remain confidential. At no time will we ask for your name, social security number, or any information that could lead to your identification.

By completing the survey you are agreeing that you understand the study and that you agree to take part in this study. You will be given a copy of this information sheet.

APPENDIX B

Demographic Data

1. What is your age? _____ .
2. Marital Status. _____
3. Do you live alone? .. Y / N
4. What is the highest level of education you have attained? 0-6 / 7-12 / 13-16 / 17+
5. Race? Caucasian / African American / Asian / Hispanic / Other _____
6. What is your religious preference? .. _____.
7. Who provides the most support for you? .. ___ Wife, ___ Physician, ___ Church,
___ Support Group, ___ Friends, Other _____.
8. If you are a member of a support group, how long have you been an active member?
_____ years, _____ months
9. Do you have any family members with prostate cancer? Y/N
10. Military Status ..AD / RET
11. Branch of Service Army / Air Force / Navy
12. Rank .. _____.
13. What stage was your disease when you were diagnosed. _____ .
14. How long ago were you diagnosed? _____ .

APPENDIX C

Mishel Uncertainty In Illness Scale — Community Form

Instructions:

Please read each statement. Take your time and think about what each statement says. Then circle the column that most closely measures how you are feeling TODAY. If you agree with a statement, then you would circle either Strongly Agree (5) or Agree (4). If you disagree with the statement, then circle either Strongly Disagree (1) or Disagree (2). If you are undecided about how you feel, then circle Undecided (3) for that statement. Please respond to every statement.

1 = Strongly Disagree 2 = Disagree 3 = No Opinion 4 = Agree 5 = Strongly Agree

1. I don't know what is wrong with me. . 1 2 3 4 5
2. I have a lot of questions without answers. .. 1 2 3 4 5
3. I am unsure if my illness is getting better or worse. ... 1 2 3 4 5
4. It is unclear to me how bad my pain will be. . 1 2 3 4 5
5. The explanations they give about my condition seem hazy to me. 1 2 3 4 5
6. The purpose of each treatment is clear to me. . 1 2 3 4 5
7. My symptoms continue to change unpredictably. ... 1 2 3 4 5
8. I understand everything explained to me. 1 2 3 4 5
9. The doctors say things to me that have many meanings. . 1 2 3 4 5
10. My treatment is too complex to figure out. .. 1 2 3 4 5
11. It is difficult to know if the treatments or medications I am getting are helping me.
. 1 2 3 4 5
12. Because of the unpredictability of my illness, I cannot plan for the future.
1 2 3 4 5
13. The course of my illness keeps changing. I have good days and bad days.
..1 2 3 4 5
14. I have been given differing opinions about what is wrong with me. 1 2 3 4 5

15. It is not clear what is going to happen to me. .. 1 2 3 4 5
16. The results of my test are inconsistent. ... 1 2 3 4 5
17. The effectiveness of my treatment is undetermined. 1 2 3 4 5
18. Because of the treatment, what I can do keeps changing. 1 2 3 4 5
19. I m certain they will not find anything else wrong with me. . 1 2 3 4 5
20. The treatment I am receiving has a known probability of success. 1 2 3 4 5
21. They have not given me a specific diagnosis .. 1 2 3 4 5
22. The seriousness of my illness has been determined. .. 1 2 3 4 5
23. The doctors and nurses use everyday language so I can understand what they are
saying. 1 2 3 4 5

Comments:

APPENDIX D

Data Dictionary for Uncertainty in Prostate Cancer

Variable	Code
1. Age	Two digits
2. Marital Status	s-single, m-married
3. Do you live alone	y=yes, n-no
4. Education	0-6 =1, 7-12 =2, 13-16 =3, 17+ =4
5. Ethnicity	cau-caucasian am-african american asian-asian hisp-hispanic other-other
6. Religious Preference	cath - catholic prot - protestant jew — jewish
7. Who provides most support	wife - wife church - church supgr - support group other — other
8. If you are a member of a support group, how long have you been an active member?	Two digits
9. Do you have any family members with prostate cancer?	y = Yes n = No
10. Military Satus	1 = Active Duty 2 = Retired
11. Branch of Service	1 = Army 2 = Air Force 3 = Navy/Marines 4 = Coast Guard
12. Rank	1.1—1.9 = E-1 — E-9 2.1-2.9 = O-1 — O-9

3.1-3.4 = W-1 — W-4

13. How long ago were you diagnosed

Two digits

14
through
37

Score 1-5

Appendix E: USUHS IRB Approval



UNIFORMED SERVICES UNIVERSITY OF THE HEALTH SCIENCES
F. EDWARD HEBERT SCHOOL OF MEDICINE
4301 JONES BRIDGE ROAD
BETHESDA, MARYLAND 20814-4799



July 13, 1999

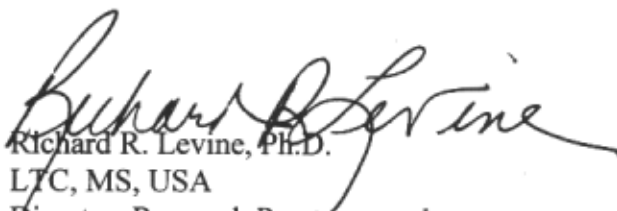
MEMORANDUM FOR CAPT JAMES L. SALL, USA, GRADUATE SCHOOL OF NURSING

SUBJECT: IRB Approval of Protocol **T061AQ-01** for Human Subject Use

Your research protocol entitled "*The Effect of Support Groups on Uncertainty in Prostate Cancer*," was reviewed and approved for execution on 7/12/99 as an exempt human subject use study under the provisions of 32 CFR 219.101 (b)(2). This approval will be reported to the full IRB scheduled to meet on 12 August 1999.

The purpose of this study is to compare the uncertainty experienced by men with prostate cancer attending a support group and those with prostate cancer who do not. A sample of prostate cancer support group patients and non-support group patients from the WRAMC Urology Clinic will be surveyed regarding their apprehension about the disease and their treatment. The IRB understands that no sensitive or subject identifying information will be collected as part of this study and all data will be reported in the aggregate.

Please notify this office of any amendments you wish to propose and of any untoward incidents which may occur in the conduct of this project. If you have any questions regarding human volunteers, please call me at 301-295-3303.


Richard R. Levine, Ph.D.
LTC, MS, USA
Director, Research Programs and
Executive Secretary, IRB

Cc: Director, Grants Administration

Appendix F: Walter Reed Army Medical Center IRB Approval



DEPARTMENT OF THE ARMY
WALTER REED ARMY MEDICAL CENTER
WASHINGTON, DC 20307-5001

REPLY TO
ATTENTION OF:

MCHL-CI

23 July 1999

MEMORANDUM FOR LTC Janice B. Agazio, AN, Nursing Research Service,
Department of Nursing, Walter Reed Army Medical Center,
Washington, DC 20307-5001

SUBJECT: Proposed Clinical Investigation Research Protocol - Exempt from Review

1. Your protocol entitled "The Effect Of Prostate Cancer Support Groups On Uncertainty In Prostate Cancer" was received in this department on 19 July 1999 and a revision was received on 22 July 1999. This protocol has been reviewed by MAJ R. Michael Tuttle, MC, Asst Chief, Department of Clinical Investigation and the undersigned.
2. Per Army Regulation 40-38, Clinical Investigation Program, Appendix B, paragraph B-5, and WRAMC Regulation 70-1, Clinical Investigation Program, WRAMC Research Activities, the research outlined in the proposed protocol meets the criteria for a study in Public Behavior and is exempt from further review by WRAMC Clinical Investigation Committee and/or Human Use Committee.
3. Your research protocol has been assigned Work Unit #75008E-99. It will be reported as exempt to the Human Use Committee (HUC) on 24 August 1999. You may begin the study upon receipt of this letter for a survey of up to 200 men. Please be reminded that any subject's personal identification needs to be coded during the data collection in order to protect their privacy and any indirect linkage must be destroyed after data collection is complete.
4. No funding was requested from DCI. **Per exempt guidelines no other resources, such as supplies or statistical and computer support, are available.**
5. If you have any questions, the POC is Vicki Miskovksy at (202) 782-7833.

Audrey S. Chang

AUDREY S. CHANG.
Ph.D., DAC
Chief, Research Review Service
Co-Chairperson, Human Use Committee

cf: Chief, Research Administration Service

Appendix G: MUIS-C Permission

Request Form - MUIS-C

I request permission to copy the Adult Uncertainty in Illness Scale (Community Form) for use in my research entitled

Uncertainty in Prostate Cancer

In exchange for this permission, I agree to submit to Dr. Mishel, upon completion of the study a printout of the uncertainty data on a 3.5 inch disk containing the data with the data dictionary. The data must contain information on each subject's age, sex, education, and diagnosis, along with data on each subject's response to each item on the *Uncertainty Scale*. This data will be used to establish a normative data base for clinical populations. No other use will be made of the data submitted. Credit will be given to me in reports of normative statistics that make use of the data I submitted for pooled analyses. Credit will be given to me in any reports referring to my findings.

J. Sall

(Signature)

4/20/99

Date

Positions and full address of Investigator

CPT James L. Sall

Student (MSN) Uniformed Services University

3405 Chelsea Dr.

Woodbridge, VA 22192

Permission is hereby granted to copy the MUIS for use in the research described above.

Merle H. Mishel

Merle H. Mishel

4/20/99

(Date)

Please send two signed copies of this form to Merle H. Mishel, PhD, FAAN; School of Nursing, CB #7460 Carrington Hall, University of North Carolina, Chapel Hill, NC, 27599-7460